

Consumers Speak Through Medicaid Waiver Survey

I. PURPOSE

From January through June 2003, the Division of Senior Services (DSS) Quality Assurance Section surveyed 170 Medicaid Waiver clients regarding their satisfaction with program services. Clients on the Older Alaskan and Adults with Physical Disabilities Waivers were surveyed.

When Alaska's Mental Health Trust Authority provided the original start up funds for the (then) Division of Senior Services Quality Assurance Program, the Trust stipulated that the Quality Assurance Program survey Medicaid Waiver clients about their program satisfaction. Further, the federal Center for Medicare and Medicaid Services (CMS), the Medicaid Waiver funding agency, has asked states to survey waiver clients. CMS provided the questionnaire used by the DSS Quality Assurance staff. This questionnaire was slightly modified by DSS, based on suggestions by Alaska's Medicaid staff.

The purpose of the survey was to provide an overview of the Medicaid Waiver Program for two waivers administered by DSS: the Older Alaskans Waiver and the Adults with Physical Disabilities Waiver. The 29-page survey was administered by a Quality Assurance staff person, using in-person client interviews in their homes or in their Assisted Living homes. Surveys were conducted in Anchorage, Fairbanks, Juneau, Mat-Su Valley, Palmer, Kenai, Soldotna and Homer. Telephone interviews were attempted with outlying communities, but this effort was not successful due to the length of the interview and the frail nature of many clients.

The survey is not intended to be scientifically accurate, but rather an attempt to measure the perceptions, experiences and opinions of the consumer. The information gained from the survey will be used to provide guidance to Medicaid waiver administrators and policy makers.

Specifically, the goals of the 2003 Medicaid Waiver Consumer survey were to:

- Evaluate consumer satisfaction with the various parts of Medicaid services, including care coordination, chore, transportation, respite, meals, adult day care and personal care attendant services.
- Use the consumer feedback as a basis for improving or altering methods of service delivery and evaluating program provider performance.
- Comply with CMS and Mental Health Trust Authority requirements to survey Medicaid Waiver clients.

Since the completion of this survey in June 2003, the Division of Senior Services has been reorganized and has become the Division of Senior and Disabilities Services (DSDS). DSDS is now responsible for two additional Medicaid Waivers: the Development Disabilities Waiver and the Children with Complex Medical Conditions Waiver. The Quality Assurance Program will continue to interview Medicaid Waiver clients for client satisfaction.

II. THE SURVEY INSTRUMENT

In October 2002, CMS invited Division Deputy Director/Quality Assurance Program Manager Cristina Klein and Project Assistant Liz Donnelly to a seminar with five other state representatives testing the CMS survey instrument and sharing their experiences. Liz Donnelly worked with Division of Senior & Disabilities Services (DSDS) staff to modify the survey slightly with additional questions. The final draft was reviewed by Director Steve Ashman, and by Jon Sherwood and Barbara Knapp of the state's Medicaid program. The final version of the survey has seven sections covering service provision.

1. Care Coordination: twenty
2. Chore: fourteen questions
3. Transportation: eleven questions
4. Adult Day Services: fifteen questions
5. Meals: eleven questions
6. Respite: eleven questions
7. Personal Care Attendant (PCA): sixteen questions

A general information section provided clients the opportunity to rate their satisfaction with the Medicaid Waiver programs. Clients were asked to identify what they liked and did not like about the program.

The survey included more questions about care coordination. Unlike any other services, all clients have care coordinators who develop the Plans of Care for clients and therefore are the primary focal point for client services and for resolution of problems with services.

The (then) Division of Senior Services created a 6-month, non-permanent project assistant (range 16) position to conduct the survey. Suzanne Seigfreid began work in January 2003. She was not acquainted with any of the clients, care coordinators, service providers, or Division staff. Ms. Seigfreid has a degree in Healthcare Administration and extensive experience working with the senior population in other states. She also has experience as a licensed nursing home administrator and opened Alzheimer units for Hillhaven Corporation, experience as a certified case manager and trainer, and most recently as a Title V older worker employment manager for central Nebraska.

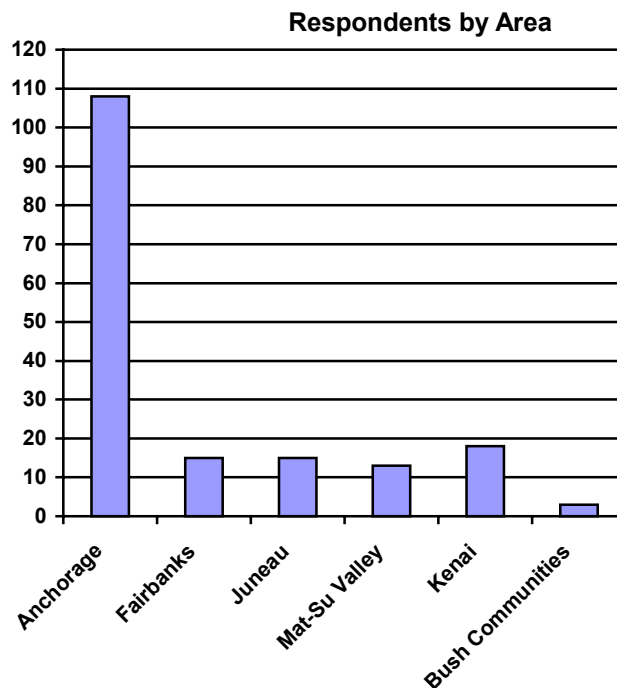
Ms. Seigfreid is neither a licensed RN nor a licensed Social Worker in Alaska. Therefore, according to the terms of Alaska's Older Alaskan and Adults with Physical Disabilities Waivers, she cannot officially make Waiver Level of Care determinations. Her

impressions about whether or not Waiver clients appear to meet Waiver Level of Care are her impressions only and cannot be considered as determinations for eligibility. However, given Ms. Seigfreid's experience, her impressions are considered sufficiently accurate to inform Division policy makers.

Care coordinators were informed about the survey in the January 2003 via the Division Medicaid Waiver newsletter. The survey instrument was posted on the Quality Assurance web page. Copies were made available at the reception desk of the Division office. Deputy Director Klein sent out announcements and information about the questionnaire to all Care Coordinators.

Clients were informed that the survey information would be completely confidential. All copies of questionnaires with identifying information on them were destroyed. The Division has only retained data with no identifying information.

Jan Dickey, the Division's Data Integration Coordinator, drew a random client sample. Letters were sent to all clients whose names had been selected informing them that they had been chosen for the survey process. The letters explained that Ms. Seigfreid would contact them to arrange for an interview at their convenience, assured them that all information would be confidential, and emphasized that their participation in the survey was voluntary.



The only exception to confidentiality was that of clients in dangerous or harmful situations. The surveyor was instructed that if clients were found in dangerous situations, that information should be reported to Adult Protective Services. Fewer than 10 such

situations were found during the course of the interviews, and these were all reported to Adult Protective Services for follow up action.

If a client requested specific assistance or information from the surveyor, the client was provided with that information or referred to the appropriate support source. All of the clients surveyed were provided information about their rights as waiver clients, and they were given a magnet with Division contact information in large type.

All the surveys in Anchorage, Fairbanks, Mat-Su, Seward, Kenai, and Juneau were conducted in person. The clients reported their experiences by responding to the questions on the 29-page survey. Clients were encouraged to add any comments and respond in an open-ended interview format. The interview process took over an hour, and the majority of clients reported satisfaction with the process. On occasion, a client was too frail to complete the interview or did not feel well enough to do the interview, despite prior arrangements.

Responses were recorded on the paper questionnaire and later transferred to an electronic database. To ensure the confidentiality of clients and their comments, a number was assigned to the client at the onset of the interview, and the paper survey was destroyed after it was entered into the database.

III. ISSUES ENCOUNTERED

- Numerous incorrect addresses. Over half of the clients had moved within the past year. The Division's Waiver staff was informed of these errors.
- About 25% of the people contacted couldn't be interviewed because of their medical conditions. (Dementia, unable to speak, too ill to participate, etc.)
- Several clients had died, and the Division hadn't received notice. This information was provided to the Medicaid Waiver staff.
- 6 clients declined to participate.
- 3 clients in the Fairbanks area had entered a nursing home and therefore couldn't respond.
- 5 clients were vacationing, three in the lower forty-eight and two in Hawaii, and were unable to respond.
- Several clients had no phones and could not be reached to arrange for an interview.

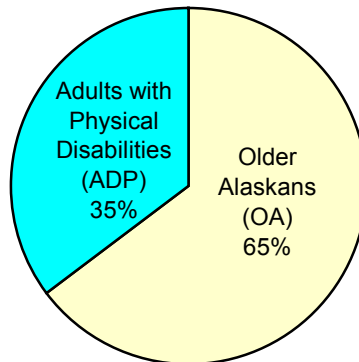
IV. GENERAL INFORMATION ABOUT THE SURVEY

A total of 340 letters were sent to clients informing them that they had been randomly selected for the survey process. Anchorage and the Matanuska Valley area received the largest share, with 240 being notified of a potential interview. The remaining 100 letters were sent to towns on the Kenai Peninsula, Fairbanks and Juneau.

The surveyor personally met with 228 clients who received the letter/notice, though only 170 of these were willing and able to participate. Of the 170 interviews, 60 were conducted with clients on the Adults with Physical Disabilities (APD) waiver, and 110

clients interviewed were on the Older Alaskan (OA) Waiver. Eighteen (18) clients died between the time they were sent a letter and the day of the interview.

Survey Respondents by Waiver Type



V. SURVEY RESULTS

Note: Not all clients responded to all questions. The reasons for the lack of responses ranged from clients being too frail to complete the full interview, refusing to answer specific questions, or not have the services covered in a particular section of the questionnaire. Medicaid Waiver clients do not receive the same and/or all services covered in the questionnaire. Therefore, the numbers reported in any given section do not usually correspond to the total number of clients surveyed.

The Questionnaire:

Section 1—General Information

Positive Comments

- 86% of clients surveyed reported they were satisfied or very satisfied with the Older Alaskan and Adults with Physical Disabilities Waiver Programs.
- 2% reported that the program was outstanding.
- 58% of the clients interviewed had been on the program two years or longer.
- 88% participated in their decision to receive home and community based services rather than entering a nursing home. 12% relied on guardians or family to make these decisions.
- When queried about what participants specifically liked about the Choice program, the following were some of the responses noted: “appreciate the help,” “program has greatly enhanced my quality of their life,” “liked help with cost of medications.”
- When questioned about what they didn’t like about the program, about 95% responded with: “what is there not to like?” or “nothing.”
- The most common response when asked what Medicaid could do to make it easier to be at home was “nothing.” The next most common response identified a piece of

durable medical equipment they felt would assist them. Equipment most often named was electric wheelchairs or electric scooters. Clients on the Older Alaskans waiver made this comment: clients on the Adults with Physical Disabilities Waiver seemed satisfied that they had the equipment they needed.

- The common response to the question about what would make their life happier was: “I’m happy with my life now.” The next most common response was: “good health”, followed by naming a piece of equipment like an electric scooter that they would like to make their life easier.

Negative Comments

- 12% of clients reported general dissatisfaction with the Waiver program. Some of these comments appear under the specific categories that follow. This 12% of comments about dissatisfaction was fairly evenly distributed across all geographic areas where the interviews were occurred.

Section 2—Care Coordination

Positive Comments

- Most of the clients were unable to state their rights but were familiar with them after the surveyor read them to the client.
- The care coordinator sees that the client’s needs are being met.
- The care coordinator has set up a good network of providers for the client.
- The care coordinator helps the client to access services for which the client is eligible.
- The care coordinator is always looking down the road for what the client may need and helps the client do things (like arrange for services) that the client used to have to do for herself.
- The care coordinator is a great help. The client wouldn’t know what to do without the care coordinator.
- The care coordinator goes beyond the usual scope, and helped the client rent a U-Haul for a move into Assisted Living, as well as keeping an eye out for special events the client would like to attend, then transports the client to these events.
- When asked to discuss what are some of the things that the care coordinator helps you with, common responses included being helped to obtain equipment and medications, and helping solve problems.

Negative Comments

- The surveyor encountered about 15% of the clients who wanted to change care coordinators. Examples of reasons cited were: the care coordinator had “dropped the ball”; care coordinator didn’t submit paperwork on time, resulting in the client receiving notice that they were going to lose services; care coordinator had not advocated enough on the client’s behalf; and the client had to arrange medical assistance for his/her self because the care coordinator failed to do so. One client reported having to coordinate her own follow-up and discharge services after a major hospitalization.
- When asked whom they would call if they were unhappy with their care coordinator, approximately 90% percent didn’t know. The second largest response was they would

call their care coordinator. All clients were given magnets with Division contact numbers.

- 25% of the clients responded that they never call their care coordinator, but knew how to, when asked if they were able to contact them. They did not know, however, who to call (the Division or the Care Coordination agency) if they wanted to change care coordinators.
- The highest percentage of clients who responded that they didn't know they could change care coordinators lived in Juneau.
- Many clients did not respond to the question "What would you change about care coordination to make it better?" Those that did stated that the care coordinators should have smaller caseloads so that they would spend more time on each client. Some individuals reported working with new coordinators whom they felt needed more training.

Section 3—Chore Service

Positive Comments

- When asked how the chore service helps them, clients most frequently responded that chore workers "do the things I can no longer do for myself". Several clients responded that chore work "saves their strength, they would be sicker or dead if they had to live in filth." Some clients reported they enjoyed the novel situation of having a "housekeeper" for the first time in their lives.
- Vacuuming and changing bed linens were the two things most mentioned for which clients needed a chore person.
- Several clients had the chore worker perform chores such as planting and watering gardens, while others had them help with pet care i.e.: clean birdcages, walk the dog, clean litter boxes, and so on.

Negative Comments

- Chore service also generated the most complaints. Clients reported that they felt the chore workers were ill trained and disrespectful of clients and their possessions. Other complaints included worker turnover, not showing up, bringing their children, stealing from the client, and falling asleep on the job. *Almost every client interviewed related a negative service experience with a past or current chore worker.*
- Many homes that the surveyor visited had a chore worker, but the home did not appear to be neat and in order. Some homes were so untidy, despite having Chore services, that the surveyor found it difficult to move around safely in the home.
- Changes suggested by clients included screening workers better and paying them more. Workers' pay varies, but workers complain to clients about low pay.

Section 4—Transportation

Positive Comments

- Most clients used the transportation system for medical appointments, but some used it to get to jobs. One used it to go to a Title V position, two clients had positions with

the ARC of Anchorage (Association of Retarded Citizens), 3 worked with Foster Grandparents and one held private employment at a retail store.

- If no transportation were available, most clients responded that they would get around by utilizing family and friends.
- When posed with the question of “How do you think your life would be different if you didn’t have transportation?” Individuals responded in various manners. Almost all replied they would be isolated. Most said they would find the means to get around. Very few didn’t have other options.

Negative Comments

- Clients in Wasilla and Soldotna reported suspected abuse of the transportation system by clients using transportation to go out shopping, “joyriding”, or socializing.
- In response to the question of how do transportation services help you; the most common response was that it got them to medical appointments. The second most common response was that they had quit using the system because of the unreliability of scheduling times for appointments.
- Each individual surveyed was asked if they could change something about transportation services to make it better, what would they change? This question generated a flood of responses in the Anchorage area. Approximately half of the clients interviewed had quit using the system because it was so unreliable. Suggestions were: more vans needed, and one van should be designated to pick up people from home and one to pick up from their destination. Many clients reported being left for hours or never being picked up from their medical appointments.

Section 5—Adult Day Services

Positive Comments

- 10 clients interviewed participated in Adult Day Services.
- Clients stated that Adult Day Services improved their quality of life immensely through the activities offered and the opportunities for socialization.
- The kinds of activities most enjoyed in this environment were field trips and getting out of the home.
- There was a 100% satisfaction rate with this service.

Negative Comments

- The major concern was that the activities they had to pay for added up and drained their limited budget. While transportation on field trips was free, clients had to pay for their own admissions (zoo is free) and their own movies and sodas.

Section 6—Meals

Positive Comments

- None of the men interviewed complained about the meal service.
- Foods served in Anchorage included a fresh fruit and milk, which the clients stated they liked.

- The friendly person delivering the meals was the overwhelming benefit everyone receiving meals identified and liked. Individuals interviewed stated they enjoyed the social contact and having someone “check” on them daily.

Negative Comments

- Approximately 90% of the people interviewed had complaints about this service or were no longer using it. These users were primarily female. Few men were found to be living alone and depending on this service. (This complaint was forwarded to the Alaska Commission on Aging staff responsible for grants to the Meals on Wheels Program, and the Division has since learned that there is a new provider in the Anchorage area.)
- Those that were on restricted diets complained that the food provided did not meet their needs.
- Complaints on this service included: “the meat was too tough to eat”, “meal came sloppy”, “the portions are too small.” Many clients had dropped the service because “it was so terrible”.

Section 7—Respite

Positive Comments

- All the clients interviewed about this service reported favorably. Clients enjoyed having someone sit with them, and they enjoyed the opportunity for socializing.
- Family members reported that they were pleased with the opportunity to take a vacation or a break and not worry about their loved ones.

Negative Comments

None

Section 8—Personal Care Attendant Service (PCA)

Positive Comments

- Clients who received consumer-directed PCA, rather than agency-based PCA, reported high levels of satisfaction with the program.
- The surveyor estimated that approximately 25% of clients reported using their PCA mainly for running errands and shopping services.
- The PCA’s who could do massage were especially appreciated. (Massage is not a covered Waiver service, but some PCAs provide massage as part of their personal care service.)
- When questioned whether the client felt comfortable asking for changes in their service plan, the majority of clients responded in the affirmative. Those that replied no stated “they didn’t want to rock the boat.”

Negative Comments

- Many clients reported “modesty” issues and were uncomfortable using this service even though they acknowledged they could use the assistance.
- A common complaint was that they didn’t like people being sent over “green”.

- Clients stated they were “tired of training people”.
- To improve this service, clients mentioned the need for improved training by the agencies and better screening of workers.
- The clients who were on oxygen expressed irritation that their workers were not informed on how the process of tubing, etc., worked.

Section 9—Other: Consumer Concerns

Note: The following are concerns recorded as additional comments by clients.

Positive Comments

None

Negative Comments

- Clients disliked Care Coordinators and other service providers bringing their children on monthly visits or scheduled service times.
- Workers behaving unprofessionally. Clients stated “they did not want to hear about all their workers’ problems, they had enough of their own.”
- Lift chairs shutting down during electrical outages and the clients not being able to get out of them. One son went as far as to purchase a generator for his mother’s chair after she was “stuck” in it for 12 hours.
- Individuals surveyed stated they experience increased stress as a result of multiple service providers “coming and going” in their home.
- Due to age and illness, clients reported social isolation and lack of control over their lives that depressed them.
- Clients disliked having their hours for services decreased without having input in the process.
- Expressions of concern over possible Medicaid cuts and the potential loss of services.
- A majority, at least 75%, of individuals surveyed expressed frustration with service providers who “did not do their job.” These clients stated that, rather than helping the client, these service providers often created bigger problems.
- Clients reported a lack of respect for the clients and their homes and commented on the following abuses: workers sleeping in client’s beds, staying in client’s home after they had finished working (to get their hours in or to socialize), workers wearing the clients’ clothes, workers putting their feet up on the couch, workers helping themselves to food, workers changing the channel on the TV to the station they wanted to view (rather than client’s choice), and preaching from the Bible to them without asking permission.
- Clients expressed frustration that durable medical equipment purchased with tax dollars through the Medicaid program did not return to a general pool of equipment to be re-distributed to other people in need. (DSDS now provides information that equipment can be donated to various agencies.)
- Concerns on how to pay for dental work and eyeglasses were also noted by clients.
- Clients mentioned the difficulty of finding a physician who would accept Medicaid/Medicare patients.

- The length of time it took to get needed equipment and environmental modifications was voiced as a concern.
- Consumers wanted to be fully informed on all their choices. Many did not realize there was more than one agency that could provide services. One client expressed irritation that her care coordinator was dictating what agency she would be using for prescription drug service instead of her being able to choose the company she had dealt with in the past.
- Clients felt they needed education on what to expect from services and suggested the State provide written guidelines as to what kinds of things care coordination, chore, respite, PCA should be doing for them.

Surveyors' Comments and Observations

- The surveyor made numerous attempts to contact clients during the survey process. Some of the reasons that prevented the surveyor from interviewing clients were: one was attending classes at UAA, several had gone on vacation, a client was somewhere in the state in their RV, one was "down at the VFW", and one client was out on the client's boat fishing.
- The clients who were not completely bedridden reported *they could do without the services but not without the prescription drug coverage of the program.*
- Out of the 170 clients interviewed, 50 required further assistance in resolving an issue about some aspect of their care. (These were referred to appropriate agencies, though Care Coordinators should handle these problems.)
- Medicaid consumers were uninformed as to how to proceed when changing care coordinators.
- About 10% of clients in all regions reported moving to Alaska specifically to be on the Medicaid program because it was so much better than other states.
- The most desired piece of equipment to enhance the consumer quality of life was an electric scooter.
- The clients residing in independent senior housing (not Assisted Living) appeared to be the least likely to meet the required level of care for the waiver program.
- In the surveyor's non-professional (that is, not a licensed RN nor licensed Social Worker in Alaska) opinion, approximately 28% of the clients interviewed did not meet the required Nursing Facility level of care for waiver program enrollment, with the highest percentage of those residing in the Matanuska Valley.
- Obesity-related medical conditions were a factor in why some clients were on the program. Of 5 clients interviewed with extreme obesity, one had gastric bypass surgery paid for by Medicaid Waiver.
- Some items that Medicaid Waiver paid for were: stationary bicycles, magnetic therapy wraps, weight loss surgery, organ transplant, and an outside elevator lift so that one client could get into her second story apartment.
- Almost all clients expressed appreciation for the program and the help that they were receiving.
- Assessments were sometimes inaccurate. For instance, one client's assessment stated she was on oxygen 24 hours a day, yet the interview was conducted with her not receiving any. Another client's assessment stated she had mobility issues. The

surveyor arrived to find her smoking in front of her housing complex and followed her as she climbed up three flights of stairs to get to her apartment.

- Addresses were incorrect. The survey sample turned out to be a very mobile group of people. One 91 year old had moved three times within a 10-month period.
- It appeared to the surveyor that the sickest people on the program had the most problem with receiving appropriate services. This observation might merit additional study as it was unclear to the surveyor why this occurred.

DIVISION RESPONSE

NOTE: On July 1, 2003, the Division of Senior Services was transferred from the Department of Administration into the Department of Health & Social Services and became the Division of Senior & Disabilities Services. At that time, the Division's responsibilities were expanded to include oversight for two additional Medicaid waivers: Developmental Disabilities (DD) and Children with Complex Medical Conditions (CCMC).

The Division is in the process of making several changes in response to the information gained from this survey, as well as information learned through Long Term Care staff monitoring visits and complaints received by the agency.

These include:

- As of January 2004, care coordinators will no longer perform assessments of OA and APD waiver clients. The agency will contract with Licensed Registered Nurses and Licensed Social Workers to perform Medicaid Waiver assessments and make Level of Care determinations, as well as provide general guidance for the Plan of Care developed by Care Coordinators. This will speed up entry into the waiver program and improve the quality of assessment information received by the Division. Care coordinators will continue to develop specific Plans of Care and to provide on-going service to clients.
- The Division's Quality Assurance Unit now has six full time staff. These staff will continue to randomly survey waiver clients and will increase monitoring efforts for all four waivers. QA staff will also expand training of care coordinators to include training for DD waiver care coordinators. The agency will continue to seek State General Funds to match Medicaid funds supporting the program. Currently Mental Health Trust Authority start-up funds provide the Medicaid match.
- The Division is implementing a database management system that will provide electronic sharing of information. This will improve efficiency and accuracy, and it will mean better service for clients.
- The Division will make survey results available to all providers so that they can see strengths and weaknesses.
- The Division will provide explore possible training for providers to address information gained from the consumer surveys.